TOILET TRAINING FOR CHILDREN WITH AUTISM

Davina Richardson explores the effects on children with autistic spectrum disorder of late toilet training and the importance of beginning it early.

TOILET TRAINING is one of the key developmental milestones of early childhood, and there is a growing body of evidence suggesting that this skill is now being taught later than was the case 50 years ago. This article explores the reasons why this is happening and considers the effect on children with autism and related conditions. It also examines the literature to discover the approaches to toilet training for this group. Research into this area has generally focused on small numbers of children and incorporated modified versions of Azrin and Foxx's (1971) rapid toilet training method. Suggestions are offered about the most appropriate advice to give parents and carers of children with autism and related disorders, and the importance of addressing toilet training at an early stage.

Abstract

Toilet training is one of the key developmental milestones of early childhood and there is growing evidence that it is now being initiated later than it was 50 years ago. This article explores the reasons why this is happening and considers the effect on children with autism and related conditions. It also examines the literature to discover the approaches to toilet training for this group. Research into this area has generally focused on small numbers of children and incorporated modified versions of Azrin and Foxx's (1971) rapid toilet training method. Suggestions are offered about the most appropriate advice to give parents and carers of children with autism and related disorders, and the importance of addressing toilet training at an early stage.

Keywords

autism, child health, continence products, developmental disorders, developmental milestones, incontinence, toilet training

Autism and toilet training

Children with autism have problems with social communication, social interaction and imagination. As a result, they may find it difficult to understand what is being asked of them and may not be motivated by a desire to please their parents or carers as well as possibly being unconcerned about
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wearing nappies at an age when other children want to wear pants. These children may also be hyper- or hyposensitive to sensory stimuli. For the hypersensitive child the bright lighting, extractor fan noises, smells of cleaning and personal hygiene products that most people barely notice can be distracting, distressing or unbearable.

Hyposensitive children may have reduced awareness of their own body signals and struggle with balance, so may feel unsafe and frightened when sitting on the toilet.

Children can be hypersensitive to some stimuli and hyposensitive to others. However, their altered responses to sensory stimuli may result in them exhibiting fear or anxiety about changes to their routines and using repetitive movements for stimulation or to deal with stress, all of which can interfere with toilet training (MacAlister 2014).

The difficulties with information processing that are experienced in people with autism can make the world seem unpredictable. This results in the child having a reduced understanding of what is expected and/or increased anxiety levels, which may be manifested as behavioural changes or as resistance to learning the skills required for toilet training.

Problems processing sensory information also reduce the likelihood of the child exhibiting what are usually considered to be signs of readiness to use the toilet, such as showing awareness of a full nappy, expressing a desire to wear pants, being able to imitate others, wanting to please, being willing to accept changes to their routine and being able to communicate their needs. In addition, some children with autism have a restricted dietary and fluid intake, which increases the risk of constipation.

There is evidence that making sure children have an appropriate fluid intake for their age and size can help with continence issues (Van Laecke et al 2009). However, such fluid intake goals may be difficult to achieve for children with autism due to poor awareness of thirst, hypersensitivity to flavours, reluctance with changing routines, inability to transfer skills or the need to retain control.

Hyams et al (1992) recognised the detrimental impact of failing to toilet train on individuals and their carers. Their ten-year follow-up study demonstrated that intensive individual toilet training programmes were effective.

Despite this and more recent research evidence about toilet training children with disabilities (Rogers 2002, Harris 2004, Brown and Peace 2011), and the availability of some useful information and tools to support toilet training, there is a lack of consensus about the right time to start toilet training (Kaerts et al 2012). This may be exacerbated by low expectations about children with disabilities, or a tendency to delay toilet training while other problems are addressed.

Healthcare professionals may feel unable to give advice in an area where most parents or carers manage without support and there is little formal training. Harris (2004) has referred to a lack of standardisation of practices for the toilet training of children with disabilities, while Rogers (2002) has pointed out that failure to toilet train may be due to a continence problem that is not linked to the disability. A delay in attempting toilet training and an acceptance of incontinence without conducting a comprehensive bladder and bowel assessment is inappropriate.

The cost of incontinence to the child, their family and society is widely recognised. Incontinent children are more likely to be socially excluded, they are at increased risk of abuse and are more likely to require long-term residential care as adults and this all amounts to a reduced quality of life (Harris 1999). Parents of incontinent children with disabilities are reported to experience more stress than parents of children with disabilities who are toilet trained (Kroeger and Sorensen 2010).

The use of nappies has environmental costs (relating to manufacture, refuse collection and disposal) as well as financial costs (relating to both the products and the time required for changing which will often take longer than assisted or independent toileting) (Hyams et al 1992). Children with autism and developmental disorders are also at the same risk as other children of developing health conditions, such as constipation, that may have a negative effect on toilet training. If a full assessment of toileting needs is not undertaken, these health conditions may go undetected, resulting in unnecessary and protracted problems for the child and their family (MacAlister 2014). Varying expectations, depending on culture, personal experience, and advice received from healthcare professionals, may affect the toilet training process for all children (Harris 2004).

Initiating toilet training
Choby and George (2008) have described the healthcare professional’s role in the toilet training of children without disabilities as needing an
‘understanding [of] family dynamics, assessing the child’s readiness, providing education and support, and developing short-term and follow-up goals’.

Although the role of the healthcare professional in toilet training of children with developmental disabilities is similar, it is more difficult to identify how ready the child is to start toilet training. In the author’s experience, many parents receive conflicting or unhelpful professional advice, for example, that they should wait until the child indicates awareness of a full nappy.

As previously discussed, many children with autism or developmental disorders will lack motivation to stop using nappies and will not feel a need to change a behaviour that has been part of their routine reinforced since birth. Children with autism who have always used a nappy may not be aware of it filling, and if they are, they may like the sensation of warmth and weight and the firmness of the nappy around their hips.

There is some evidence that children who are toilet trained at a later age are at increased risk of developing urinary tract infections and incontinence (Bakker et al 2002, Taubman et al 2003). However, it is difficult to know when to initiate toilet training, particularly when parents and carers are given conflicting advice and information and a sustained effort is needed to toilet train these children (Brown 2006). Emerson et al (1994) identified four factors that they considered were likely to affect the delivery of a therapeutic intervention. These were:

- The behaviours and characteristics of the service users.
- The formal or planned rules and contingencies operating within the setting.
- The informal or unplanned rules operating within the setting.
- The resources available to the staff.

These can be extrapolated directly to home or school and formal settings where children spend a substantial proportion of their day.

In the home, these factors reflect the personalities of the different members of the household, the presence of firm boundaries set by parents or carers, or the modification of such boundaries according to parental mood or circumstances, for example fluctuations when friends or family are visiting, birthdays and holidays, and the varying levels of support that are available to families at different times, such as the involvement of healthcare professionals. At school, these factors also reflect school routines, the attitudes of teachers and support staff, and expectations of their role as educators.

Felce (1998) concluded that the skills and motivation of caregivers play an important part in determining the outcome of demanding long-term therapeutic programmes. Most parents are motivated to toilet train their children and the majority are attuned to their children’s physical, spiritual and emotional needs, and appreciate the complexity of them as individuals and want them to achieve their potential. However, they may lack the confidence to initiate or pursue a toileting regimen, particularly if:

- Their child appears to become upset.
- Healthcare professionals advise them that the child does not appear to be ready for toilet training.
- It is not supported or sustained in school.
- It is having a negative effect on the parents or other family members.

To maximise the likelihood of success, they require ongoing support from healthcare and education professionals who can demonstrate that they empathise with them and understand their child’s condition and provide consistent advice.

Research-based approaches

A literature search on toilet training for children with autism and developmental disabilities reveals that most of the research has focused on small numbers of children and has used modified versions of the rapid toilet training programme developed by Azrin and Foxx (1971). This method is intense and requires the trainer to spend most of their waking hours for several days focused entirely on the child, who must undertake protracted scheduled sitting, the frequency of which is gradually reduced as the number of successful voids in the toilet increases. It would be difficult for any family to sustain such a regimen, even with professional support.

Most modified versions of Azrin and Foxx’s programme cite scheduled sitting, increased fluid intake, positive reinforcement of correct toileting and a non-punitive response to accidents. Some also involve scheduled time sitting on a chair at increasing distances from the toilet as reinforcement (Cicero and Pfadt 2002, Kroeger and Sorensen-Burnworth 2009, Rinald and Mirenda 2012).

Kroeger and Sorensen-Burnworth (2009) have highlighted that independent toileting is achieved when there is a recognition of the need to pass urine or open the bowels and an ability to undertake the activities required to go to the toilet. This means getting to the right place, manipulating clothing, getting positioned on the toilet, wiping, flushing, handwashing and finally returning to resume other...
activities. All toilet training programmes focus on developing the behaviours required for this sequence of activities.

Rinald and Mirenda (2012) found that high levels of success were achieved using a modified form of the rapid toilet training programme, even though in some cases parents had low expectations of their child's ability to develop the necessary skills.

The approach described by Rinald and Mirenda (2012) involved sitting on the toilet for 30 minutes, followed by a five-minute break. The break would be started either at the end of the sitting period, or when the child passed urine, whichever occurred first. When the child had successfully passed urine on the toilet three times, scheduled sitting on the toilet was replaced by scheduled sitting on a chair, for the same amount of time.

Initially, the chair was placed two feet away from the toilet, with the distances from the toilet gradually increasing as the child successfully moved from chair to toilet to pass urine. When the chair was 20 feet from the toilet, the chair was removed. If the child started to pass urine before they were on the toilet, they were moved there by the parent or carer and 'accidents' were dealt with quickly and with as little interaction as possible.

Rewards for successful toilet visits were gradually reduced over time. Many families would find it difficult to replicate this approach, and they would be unlikely to commit to such a regimen if they were not confident of success.

It is important that the most helpful toilet training advice for healthcare professionals to give to parents of children with autism and other developmental disabilities is identified. Work on helping children develop the skills needed for toilet training should start early, before difficult behaviours develop or escalate. Some parents do start toilet training early, including those on low incomes, where the cost of nappies is a significant part of the weekly household budget, and those influenced by grandparents who toilet trained their children young. Some parents practise 'baby-led potty training'. This approach encourages parents and carers to use timing, cues from the baby and their knowledge of their infant so that they can ‘catch’ urine or faeces in an appropriate receptacle and thus avoid or reduce the number of nappies. The method can be used from birth and as the child’s motor control and communication develop, it is argued that they will become potty trained by 18 months (www.bornready.uk).

Landa (2008) has argued that although most children are diagnosed with autism at ages three to six, about 80% of parents whose children are diagnosed with autism start to have concerns by 24 months. Landa suggests that during the first nine months of life there may be no differences between the development of children with autism and developmental disorders and that of children without such disabilities, but that differences become increasingly apparent after the age of 12 months. If this is the case, it supports the argument for introducing toilet training early on.

If routines that involve sitting the child on a potty or an appropriately adapted toilet are introduced when the child can sit independently or by 12 months old, the behavioural difficulties that can accompany changes to routine as well as anxiety about sitting with a bare bottom on the potty or toilet will be avoided. However, Landa (2008) also points to prospective studies about diagnosis of autism that suggest that some children with autism have motor difficulties, including unstable posture and hypotonia. Landa (2008) found that although some studies identified symptoms of autism in very young children, in other studies it was reported that children did not exhibit clear signs of autism until they were much older. However, Landa (2008) reported that 'regardless of the pattern of onset, any child with an autism spectrum disorder can show regression in existing skills'.

In addition, she cited substantial evidence that early intervention 'has a beneficial impact on the development of two year olds with autism spectrum disorders'. Therefore, early toilet training with
maintenance of routines and parental support can be seen to be important. However, many healthcare professionals encourage parents to delay toilet training if there are concerns about development, in the mistaken belief that children with additional needs will not be capable of toilet training until they have reached a certain level of awareness and have achieved the cognitive ability of the average three year old.

For families, the social impact of having an incontinent pre-school-age child is minimal, and the demands of coping with different behaviours related to autism or other disorders along with the appointments, the diagnosis and the emotions that surround this may mean that toilet training is delayed.

This delay has meant that many children with autism and related disorders are presenting in nursery aged three and at full-time school at four to five years of age without being toilet trained. Successful toilet training for these children requires a coherent and consistent approach to be adopted at school and at home, with professionals providing support for the child’s parents and agreeing an individualised toilet training programme.

**Resources**

It is important to help parents and carers to understand that toilet training involves learning a series of skills and support should be provided for children who are struggling, just the same way that it would be offered if they were experiencing developmental delays in other skills. For example, physiotherapy for delay in motor skills, or speech therapy for delay in language acquisition.

Assessment should precede any intervention. Parents or carers should be asked to keep an hourly record of the child’s fluid intake and output for at least four full days, so that any abnormalities can be detected and treated. The assessment may then be used to inform an individual programme for toilet training. However, if the programme is to be successful, the child needs to be able to stay dry for at least 1.5 hours at a time, be free from symptoms of constipation and have the physical ability to sit.

Many children with autism are visual learners, so a communication system such as the picture exchange communication system - where pictures are used to request items or activities and to build communication skills, social stories – short descriptions of what to expect in a particular situation to aid understanding and help to teach and model appropriate responses, and visual timetables using pictures can be useful as part of a toilet training programme. Children also need

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Healthcare professionals should provide consistent advice about toilet training based on research evidence and resources to be provided with a toilet that has appropriate adaptations, such as an insert seat or a stool to put their feet on, so that they feel safe, secure and comfortable when sitting.

Once these adaptations are in place, removal of nappies, together with increased fluid intake, regularly sitting on the toilet at times determined by fluid intake and output records, instant rewards with favourite toys or small amounts of favourite foods to provide positive reinforcement for correct toileting, a non-punitive response to accidents, and consistency usually result in successful toilet training. However, individual difficulties may require creative solutions. Use of a moderately enjoyable activity may help to promote sitting for long enough to allow the child to complete elimination.

It is important to provide the child with a means of communicating when they need to use the toilet, particularly if they are non-verbal. Awareness of sensory issues, with appropriate adjustments to the environment, for example, dim lighting, wearing socks or slippers to prevent the sensation of a cold floor under the feet, ensuring that the temperature of the bathroom is the same as that in the rest of the house, or using a weighted blanket to help the child feel ‘grounded’ on the toilet can also be helpful.

Healthcare professionals need to consider the extent to which their advice and interventions about toilet training are based on research-based evidence and to what degree they are rooted in current social norms.

It can be detrimental to advise a delay to toilet training as it can result in an increase in behaviour that adversely affects the process, or in an increased risk of urinary tract infection or incontinence, as has been suggested by Bakker et al (2002) and Taubman et al (2003).

Healthcare professionals are in a unique and privileged position in terms of their ability to understand the family’s functioning, provide an individualised assessment, suggest appropriate strategies based on the outcome of the assessment, liaise with colleagues in health care and education, provide practical suggestions and assist with the development of realistic goals.

Further research is needed into the benefits of toilet training all children at a younger age, and the best methods of achieving this, with a view...
to supporting all parents to help their children to acquire this skill. The greatest potential effect of this change will be on children with autism and developmental disabilities, who will then be acquiring a skill that is part of usual child development before difficulties with social communication, interaction and imagination and any resulting challenging behaviours, have become entrenched.

Conclusion
Toilet training is a fundamental skill that is normally acquired in early childhood, and delays in its acquisition have a profoundly negative effect on children and their families. However, many families find toilet training challenging and there is an increasing tendency to address it when their children are older than has been the norm. This means that, in children with autism and developmental disabilities, the symptoms associated with autism have become established by the time toilet training begins. Healthcare professionals should therefore promote early toilet training for all children, and provide families with support and consistent advice based on research evidence and resources.

Implications for practice
- Delays in starting toilet training for any children have negative effects.
- Incontinence should not be accepted as inevitable in children with autism or related disorders.
- Healthcare professionals have a vital role in assessing readiness for toilet training and providing education and support to parents and carers.
- It is important to work on skills for toilet training early, before challenging behaviours develop in children with autism and related disorders.

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Conflict of interest
None declared